Congress of the United States Bouse of Representatives

Washington, D.C. 20515

September 11, 2003

The Honorable Tommy G. Thompson Secretary of Health and Human Services U.S. Department of Health and Human Services 200 Independence Avenue, SW Washington, DC 20201

Dear Mr. Secretary:

We are writing to express concern about recent changes made by the Centers for Disease Control and Prevention (CDC) to programs that fund HIV/AIDS prevention efforts around the country. The changes require that HIV/AIDS prevention materials undergo an additional layer of review prior to distribution. This new requirement has yet to be justified by CDC, is not accompanied by new funding, and has caused concerns among state HIV/AIDS directors.

The new CDC policy, announced in July, applies to all AIDS prevention grants funded through CDC's intergovernmental programs. This program includes all state and territorial health departments, as well as those of some major metropolitan areas. We understand that the policy may soon be broadened to encompass organizations directly funded by CDC. We have also learned that CDC is rewriting 1992 guidelines on the content of AIDS prevention materials.

We urge you to reconsider these actions. CDC's programs to prevent HIV/AIDS play a crucial role in limiting the suffering and death caused by this illness. We believe future changes to HIV/AIDS prevention activities should be fully explained and justified prior to implementation.

Approval of HIV/AIDS Prevention Materials

The current system for review of HIV/AIDS prevention materials is designed to meet two goals: the promotion of accurate and effective life-saving education, and the assurance that all materials comply with standards on content. Under a system developed by the Department of Health and Human Services (HHS), in cooperation with state health officials and health advocates, each grantee utilizes a Program Review Panel to review all written materials, pictures, tapes, videos, surveys and educational activities that will be used in their communities. This process was created by consensus after extensive debate. Over the last decade, it has succeeded in establishing a process of local autonomy and oversight that recognizes that the HIV prevention programs will vary across geographic areas and target groups.

The Program Review Panels have historically been composed of individuals with expertise in HIV/AIDS, the local epidemiology of the disease, and the needs of affected and at-

risk communities.¹ To comply with guidelines published in 1992, the panels draw on the experience of people who "can represent cultural sensitivities and language of the intended audience." A primary purpose of the panel is to assess the "appropriateness" of HIV/AIDS education materials, which guidelines state "should use terms, descriptors, or displays necessary for the intended audience to understand dangerous behaviors and explain less risky practices concerning HIV transmission."

Program Review Panels must also ensure that materials comply with Section 2500 of the Public Health Service Act.⁵ Under this provision, all programs receiving funds must include information on "the harmful effects of promiscuous sexual activity and intravenous substance abuse, and the benefits of abstaining from such activities." Funds cannot be used for any program "designed to promote or encourage, directly, homosexual or heterosexual activity or intravenous substance abuse."

Whether materials are acceptable under Section 2500 is not left entirely to the Panels' discretion. Under the statute, the prohibition on programs that are designed to promote sexual activity or drug use may not be construed to restrict any program that provides accurate information on reducing the risk of HIV transmission, as long as the materials used do include information on the harmful effects of promiscuous sex and drug use and are not obscene.⁸

¹ Content of AIDS-Related Written Materials, Pictorials, Audiovisuals, Questionnaires, Survey Instruments, and Educational Sessions in Centers for Disease Control and Prevention (CDC) Assistance Programs, Interim Revisions, §2(a)(1) and (2) (June 1992) (hereinafter "Interim Revisions").

² Interim Revisions §3(1)(a).

³ Interim Revisions §1. According to 1992 guidelines, "no single intended audience shall predominate the composition of the Program Review Board" except that for panels reviewing materials for racial and ethnic minority populations, "membership of the [panel] may be drawn predominately from such racial and ethnic populations."

⁴ Interim Revisions §1(a).

⁵ Public Health Service Act §2500, 42 USC 300ee(b), (c), and (d).

⁶ 42 USC § 300(b).

⁷ 42 USC § 300ee(c).

⁸ 42 USC § 300ee(d).

As a result of efforts by Program Review Panels across the country, CDC-funded prevention materials are consistent with scientific evidence, are accurate and not obscene, and educate hundreds of thousands of Americans each year.

New Requirements

In the new program announcement for State and Local Health Departments' HIV Content Review Guidelines, CDC has announced immediate changes to the review process for HIV/AIDS prevention materials. 9

Most significantly, CDC has added an additional layer of approval for HIV prevention materials:

[Y]ou must include a certification that accountable state or local health officials independently review the federally-funded HIV prevention materials for compliance with Section 2500 of the Public Health Service Act and approve the use of such materials in their jurisdiction for directly and indirectly funded organizations.¹⁰

CDC has provided no definition of either "accountable" or "independently." The program announcement included no justification for this step, and no new resources are available to help states establish this process.

As you are aware, state governments are experiencing a severe budget crisis. At a time of dwindling resources, health officials must contend with multiple public health challenges, including the smallpox vaccination program, bioterrorism preparedness, and SARS preparedness. Review of all HIV/AIDS prevention materials is now another task for their attention. The National Alliance of State and Territorial AIDS Directors has commented that this requirement will stretch already-strained state health officials to their limit.

The new requirement not only imposes new costs, but does so despite a lack of evidence that the expenditures are necessary. The existing review process already requires Program Review Panels to review materials for compliance with §2500. Furthermore, many panels are already required to include a representative of the state or local health department. There does not appear to be any need for additional health department oversight of the review process.

⁹ Department of Health and Human Services, *Program Announcement 04012: HIV Prevention Projects, Notice of Availability of Funds*, 68 Fed. Reg. 41138 (July 10, 2003), amended 68 Fed. Reg. 44088 (July 25, 2003).

 $^{^{10}}$ *Id.* at §I(6)(a).

The new funding announcement also changes the requirements for panel composition. For all applicants, the CDC requires a certification that the review panel represents a "reasonable cross-section of the community in which the program is based." This language differs from the current guidelines, which state that members must represent "a reasonable cross-section of the general population." While the significance of the change is far from clear on its face, Deputy CDC Director Ed Thompson told Congressional staff that it is intended to expand the pool of people who serve on review panels beyond public health experts and members of affected groups.

We are concerned that this policy change could undermine the public health effectiveness of Program Review Panels. Currently, panelists must understand both the HIV epidemic and the target communities for HIV prevention work. People who have this expertise provide the most effective public health oversight of prevention activities.

To reduce the risk of transmission, it has been demonstrated that programs must discuss drug use and sexual behaviors in frank and culturally appropriate terms. To the extent that the new policy serves to produce review panels with less experience in HIV/AIDS prevention, it could result in materials that are bland and ineffective. Such a shift would reduce the effectiveness of HIV prevention activities and cost lives.

Future Changes to HIV/AIDS Prevention Policy

It is also our understanding that the recent changes to state HIV/AIDS prevention programs may be followed by others. According to Dr. Thompson, and as suggested by the recent program announcement for states and metropolitan areas, CDC intends to apply the new requirement for an additional layer of review to organizations that receive HIV/AIDS prevention funding directly from CDC. These grantees, which include programs supported by the Minority HIV/AIDS initiative, will apparently also be forced to change the composition of their Program Review Panels. It is our understanding that these grantees' programs will also have to be approved by state or local health officials. This requires a state health official to sign off on a program that the state itself did not fund, adding an additional layer of bureaucracy for the grantee, as well as adding an additional burden on an already overwhelmed health department, without providing them additional funding.

In addition, we understand that CDC is planning to revise the 1992 content guidelines. Such a revision could disrupt a policy that has worked for years to assure a meaningful review of

¹¹ *Id.* at §I(6)(b).

¹² Interim Revisions §3(1).

HIV/AIDS prevention materials. As far as we can see from information available to us, this change is being undertaken without analysis or demonstrated need.

Conclusion

The effective prevention of HIV transmission is too important to be burdened by unnecessary additional review procedures. We urge you to reconsider the recent changes made to CDC's HIV/AIDS prevention grants and to make any future changes only after thorough analysis and full consultation with the stakeholder groups and with Congress. We also ask that you provide answers to the following questions:

- 1. What evidence led CDC to require a new layer of review for HIV/AIDS prevention materials?
- 2. Have state or local AIDS directors, public health departments, or HIV prevention community planning groups indicated that an additional layer of review is necessary?
- 3. What evidence led CDC to change the composition of Program Review Panels?

We request a reply by September 25, 2003.

Sincerely,

Member of Congress

Steny H. Hover

Member of Congress

Member of Congress